

Editorial

The paradox of disability in abortion debates: bringing the pro-choice and disability rights communities together

There is an unfortunate paradox that arises when pro- and anti-choice advocates talk about disabilities such as Down syndrome or spina bifida.

The paradox works this way: On one hand, reproductive rights proponents can portray disability as a tragic state that justifies abortion—even for wanted pregnancies. At the same time, anti-choice advocates proclaim their value for all life, including individuals with and without disabilities. That paradox places disability rights advocates, generally a group that finds itself in the progressive political camp, on the same side as anti-choice advocates who are more usually associated with conservative political positions.

On the other hand, the anti-choice camp has never championed policies that provide services for people with disabilities and their families, such as the Regional Center system and In-Home Support Services in California and their equivalents in other states [1]. These services, considered by many political conservatives to be entitlements and thus a place to cut funding, make it possible to meet the needs of families raising children, including children with disabilities. The pro-choice side, arguing for the right to terminate these pregnancies, tends to champion funding for the social services and support programs that meet all families' needs, including families of children with disabilities. A truth often ignored by anti-choice advocates—that raising a child with a disability has financial repercussions for the child's family—means that without such services, only the affluent can provide the support many children with disabilities require to thrive.

So it seems that disability rights and reproductive rights can conflict and intertwine, particularly on the issue of later abortion. It is critical to untangle these paradoxical stances to acknowledge the disability community's perspective and to align with the values of the reproductive rights movement. As reproductive health providers and advocates, we must work to improve how we understand and talk about the intersection of disability and abortion for women, families, and society at large. Reproductive rights groups can strengthen their advocacy positions by including and respecting disability rights when fighting for the rights of women to choose how to plan their families.

On April 13, 2010, the Nebraska legislature enacted a new law making later abortion more difficult to obtain,

changing the parameters from the 24-week viability definition to a concept of the fetus' ability to experience pain at 20 weeks [2]. The primary strategy of the national pro-choice organizations involved in this fight has been to raise the specter of pre-natal diagnoses of potential or confirmed congenital disability as the rationale for protecting access to abortion in the third trimester. Unfortunately, the language used to discuss this dilemma all too frequently can be perceived as oppositional by disability advocates and others, and seems disconnected from the real-life experience of the disability community.

In attempts to personalize difficult late abortion decisions, some pro-choice organizations have recounted stories of families struggling with the “excruciating choice” to terminate a wanted pregnancy because their fetus has received a diagnosis of disability. To understand this, it is useful to have a working definition of disability. The World Health Organization's International Classification of Functioning, Disability and Health (ICF) defines “disability” as “an umbrella term for impairments, activity limitations and participation restrictions [3].” This definition covers a range of conditions that have mild to severe impacts on daily life. So mild autism, such as Asperger's Syndrome, is not definitionally distinct from a fatal condition such as anencephaly, except in degree of severity. Disability in the context of a termination decision for a wanted pregnancy has been described as a “tragedy” and a “defect”— using the language of pain, suffering, and devastation. The focus is on the potential suffering a child with a disability will allegedly experience and inevitably bring on parents and other siblings. The fetus with a disability that is survivable post-partum is often considered damaged.

On the other side of the debate, anti-abortion advocates use much more empowering language about the experience of parenting children with disabilities and living as an adult with disability. The anti-choice Abortion73.com website claims, for example, that “abortion advocates . . . argue for the right to abort children who might grow up with a disability, as if disease or handicap somehow strips a person of their right to live and relegates them to a life of misery. Such a suggestion is barbaric and inhumane and has no place in a just society. There are children of all ages, and adults

too, who are alive today and are living through all manner of disease and disability. Do these physical limitations make them less than human?" [4].

The National Right to Life Committee uses similar language: "Aborting a child with a disability or illness is the height of prejudice. When a family learns that the child they are expecting may have a special need, that family needs support and good solid medical information—not the death of their most fragile member. Society must flee this attitude that uses arbitrary yard sticks to measure peoples [sic] worth" [5].

Both approaches oversimplify the nature and complexity of disability and abortion, and neither is doing enough to provide families with the kind of support they need to have and raise children, whether or not they have disabilities. Pro-choice advocates sometimes negatively frame the issue of disability in prenatal diagnosis while fighting for social services and family support policies such as early intervention programs, special education services, family resource centers, respite care, and developmental disability services. Anti-choice advocates tend to idealize disability while opposing the entitlement programs and government funding of social services, such as state developmental disability programs, funding for the Individuals with Disabilities Education Act, and the access mandates of the Americans with Disabilities Act that would make raising a child with a disability more possible.

Ultimately, using disability language that is respectful but without policy follow-through by anti-choice advocates, and using disrespectful language but with supportive policy positions by pro-choice groups—does not serve either the reproductive rights movement or the disability rights movement. Reproductive rights groups are not anti-disability, and they are well aware of the complex challenges women face in deciding to keep or terminate a pregnancy. Unrelenting attacks on abortion rights sometimes result in pro-choice advocates choosing to use reactive messages that feature individual stories of difficult decisions in the face of fetal diagnosis rather than using family supportive and affirming messages [6]. A better message would reflect core values of dignity, human rights, and self-determination for all people and all families by including those with disabilities. The shared progressive values of the pro-choice and disability rights communities should have no place for oversimplifying disability as tragic, pitiful, or inspiring; erasing the difficulties in obtaining abortion services; and discounting family support policy agendas and their critical importance in abortion debates.

How can we break away from this paradox?

Fortunately, reproductive and disability rights approaches can combine in a way that allows reproductive rights advocates to bring their policies and messages into alignment

with their values. A disability rights approach highlights the social stigma attached to disability and the lack of environmental, social, political, and economic supports for families raising children with disabilities and for adults with disabilities. This approach positions the problem outside the person with a disability, focusing instead on the social and family supports needed to live with disability rather than on medical condition or impairment.

A reproductive justice approach advocates for an affirmative role for the government to play in ensuring that all women have the social, political, and economic power and resources to make the best decisions for themselves and their families. In the context of a prenatal diagnosis of disability, this means ensuring that women have the most accurate and comprehensive information possible, including realistic perspectives from individuals with the disability in question. A woman in this situation requires access to abortion services in a timely manner if she decides to terminate her pregnancy, and the supports necessary to sustain her family if she decides to carry the pregnancy to term. This approach shifts the discussion away from individual and private family decisions—something public policy shies away from—to a broader debate about the kinds of services, education, and supports families and individuals need to embrace disability as a part of the human experience—where positive public policy is sorely needed.

What could this cross-sectional approach of disability rights and reproductive justice have looked like in the Nebraska case of Legislative Bill 594? Here are five specific suggestions for reproductive rights advocates engaged in the debate today:

- 1) Lead with public messages that broadly communicate a values-based, family supportive position on abortion rather than engage in a public debate about the scientific accuracy of fetal pain or discussions about the legal claims being made in the case. Engaging in debates about the scientific and medical aspects of late abortions move us away from the core message of a woman's governance of her own body, and will lead to inappropriate discussions of fetal viability and which disabilities are acceptable or unacceptable. Attempts to draw medical or scientific lines mirror and reinforce anti-choice attempts to draw lines between good and bad women, and acceptable and unacceptable abortions. Scientific and medical claims evolve continually and cannot be codified into rigid policies.
- 2) Pivot away from a "pain" framework. Instead of highlighting the "pain and suffering" women and their families might experience when faced with making "tragic, devastating and excruciating" decisions, reproductive rights advocates should focus on empathizing with families facing unforeseen decisions that are unique to each family and best made within a family. They can emphasize that the role of government in each distinctive situation is to ensure the provision of comprehensive, unbiased, evidence-based information, not to force families to make certain, fixed,

and limited decisions. A move away from a “pain” framework also works to stop reinforcing and fortifying the anti-choice “fetal pain” construct where people are being asked to choose between the pain and suffering of a fetus and the pain and suffering of a woman who might have a child with a disability.

- 3) Shift the overall strategy from fetal anomaly, rape, and incest as the messaging platform for abortion to ensuring that government provides the supportive and enabling conditions for families to make the best decisions for themselves. This shift permits us to move away from a framework that judges individual women and demonizes disability, to a framework that focuses on public policies that support all families. Rather than assuming a libertarian, hands-off position for the government in these questions, reproductive rights and justice advocates can push for a strong, pro-active role for the government in providing a system for comprehensive information (including information from people with disabilities about living with disability) as well as financial and physical supports for families to make the best decisions for themselves. Support for inclusion of insurance coverage for contraception in the Affordable Care Act is a welcome step in this direction.
- 4) Emphasize and invest in the implementation of the Prenatally and Postnatally Diagnosed Conditions Awareness Act as a way to provide better information and support to pregnant women and new mothers whose fetus or newborn is diagnosed with a potential disability. This Act recognizes that comprehensive, unbiased, evidence-based information changes often, with new tests, new technologies, and new treatment options, and that public policy cannot be tied to science that is evolving rapidly and constantly.
- 5) Begin a deeper discussion about health and women’s access to abortion based on a “health” exception for the woman and the fetus in which we redefine the concept of “health” to include human variation. The current decontextualized emphasis on health implies that disability is an undesirable condition to be avoided at all costs, and it elevates a normative definition of “health” in an unrealistic way. Disability is a part of the whole human experience; no one can be guaranteed a life of perfect health without disability. By focusing so strongly on normative health, reproductive rights advocates could end up supporting access to abortion for only a very limited group of women with diagnosed health issues. This narrow approach will leave behind the women who choose abortion for many different reasons.

If the anti-choice movement has been disingenuous in their portrayal of disability and abortion, focusing on the

right-to-life rather than the right-to-live, the reproductive rights movement has not necessarily lived up to its own highest ideals either. In attempting to highlight the unique decision each woman faces when deciding whether or not to continue with a pregnancy, reproductive rights advocates have often used language that is unsupportive of disability and families living with disability. Instead of focusing on the supposed pain and suffering of disability, the movement would be more in alignment with its own values of dignity, equality and self-determination for all by focusing on messages that embrace a diversity of families and advocating for public policies that support what’s best for women and families, including babies and families with disabilities.

The disability rights framework offers the pro-choice movement its best opportunity to shift the abortion debate from a medical argument about fetal pain and viability to a positive, potentially game-changing platform on overall human rights.

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